

MINUTES
STATE ADVISORY COUNCIL FOR EARLY IDENTIFICATION
OF DEAF AND HARD OF HEARING INFANTS

Quarterly Council Meeting
Tuesday, January 25, 2018
LaPlace, Louisiana

COUNCIL MEMBERS PRESENT: Marbely Barahona (by phone), Susannah Boudreaux, Amy D'Alfonso, Gina Easterly, Jay Isch, Sohit Kanotra, Melissa McConnell, Ashley Nielsen (by phone), Leigh Ann Norman, Thira Choojitarom

COUNCIL MEMBERS ABSENT: Patti Moss

GUESTS PRESENT: Jill Guidry, Melinda Peat, Dawne McCabe, Tri Tran, Ariel Bumbala, Margaret Berry

The meeting was called to order by Dr. Choojitarom at 10:00 am. The minutes from the previous meeting were reviewed and approved as provided by motion of Dr. Kanotra and seconded by Gina Easterly with unanimous vote of attending Council members.

Council Business:

Officers:

New officers (chairman and vice chairman) for the Advisory Council for the Early Identification of Deaf and Hard of Hearing Infants (the "Council") were brought to discussion by Dr. Choo. After ensuring there is a quorum of the Council, nominations were discussed. Under the current guidelines, Dr. Choo must step down as council chair. Dr. Kanotra was nominated as chairman along with Gina Easterly. Jimmy Gore indicated his willingness to serve as vice chair. Dr. Choo is unable to serve as a member of the council since expiration of his term, but will remain as American Academy of Pediatrics Chapter Champion for the. Dr. Choo will serve as an ad hoc member, but not one of the fourteen Council spots. Dr. Kanotra volunteered to serve as Chair, and Jay Isch volunteered as Vice Chair. Unanimous vote passed for Dr. Kanotra and Jay Isch as Chair and Vice Chair, respectively.

EHDI:

Terri Ibieta shared an overview on Louisiana's Early Hearing Detection and Intervention (LA EHDI) program. Folders were distributed to every member of the Council, as well as those that will be on the Council (awaiting official signature). In the folder general information was provided included the different laws governing the Council, EHDI, the Position Statement from the Joint Committee on Infant Hearing recommendations, the AAP Guidelines, the forms currently used by our programs, the brochures used by our program. We also have brochures for the parent component, Hands & Voices, and the Parent-Pupil Education Program. We also have the EHDI contact information and the Council contacts. This also has the date you were appointed and the dates it expires. So the people not officially nominated yet, you're not included yet. Updates will be sent when needed. This is the EHDI bill that was reauthorized. After I do this presentation, Rana will go through the EHDI reauthorization with to review

changes made. Terri shared as brief presentation to provide an overview of EHDI, especially since we have new Council members. Back in 1993 EHDI programs around the country, programs only screened who were high risk. If a baby had a risk factor for hearing loss when you were born. If your child has a risk factor or if the mom had a hearing loss, then you were screened for hearing loss. Well babies were not screened. In 2002, Louisiana and now every state screens babies that are born. Not every state has a law (Louisiana does). I think maybe there are five or six that do not. Our law was enacted in 2002. It was put under the Office of Public of Health, Department of Health for implementation. Like many things in Louisiana, it was put under them but there was no funding attached. So some things that happened, these are highlights. Supervision of each hospital has to be done by an audiologist or a trained physician. So there is an EHDI supervisor at each hospital. The EHDI program at each hospital has a supervisor. It can be an audiologist or a trained physician. I'd say we have maybe five that it's a physician, every other hospital an audiologist fills this role. All newborns have to be screened before discharge. Babies that are transferred from one hospital to another, they are screened at the transfer hospital, which means they are not screened until they are ready to go home. Two screening methods may be used, Otoacoustic emissions (OAE) or Auditory Brainstem Response (ABR). If anyone wants, we have the data on how many. Now we have more hospitals using ABR only. The recommendation from JCIH is that at least NICU screened with ABR. Now that Women's Hospital is on board, all NICU babies in Louisiana are being screened by ABR. It's not the law, it's a best practice recommendation. So not every hospital screens with ABR, some NICU with ABR and well babies with OAE. Every hospital is required to complete the Followup Screening Report (FSR) which is in your folder under Forms. They report risk indicators on the form. Babies with risk indicators, even if passed their initially hearing screening, should be retested because of the risk indicator at least once within 24 months. We are hopeful that when the new Position Statement comes from JCIH that number will be reduced; twenty-four months is too long. The parents need to be provided with the results with written and verbal. The reports need to be provided to the EHDI program and to the infant's primary care provider. Of course, we all know there's an issue with babies who don't pass their Newborn Hearing Screening (NHS) becoming "lost to followup". I think our 2016 data, Tri is putting that together to go to CDC, I think its due March 2. Tri just shared recently our 2015 data. I think we are at 22% for the 2016 data. Nationally for 2015, it was approximately 28% nationally. So we are below the national average, but like Tri says, it should be 0. I don't know if it will ever be 0, but we do improve each year. Margaret Berry is doing our Community Rescreening Project. She's done it in the Natchitoches and Monroe areas. Getting to those babies that live in the rural areas. Margaret been trained on the OAE equipment and she will go to the baby's home and rescreen them. We just got some funding to also purchase ABR equipment so that those babies that are screened in the hospital with ABR, they should ideally be rescreened with ABR. She'll be trained on that too. So at our next meeting, Margaret could share information on that. Wendy Jumonville shared that she just came across the data and in 2014, the Loss to Followup was 34% nationally, and had gone down by 2015 to 28%. And too, that goes to show you that the core projects that they want worked on in the Maternal Child Health Bureau grant were all about reducing Lost to Followup, so they put funding behind it and made specific goals and objectives that they needed to meet and worked with the states to do this. Dr. Kanotra queried if there is a recommendation for doing OAE and ABR. Some facilities will do a two level screening. If they fail OAE, then they do an ABR. So for EHDI purposes, if you fail OAE but you pass ABR, you are a 'pass'. Dr. Choo shared that JCIH is releasing new recommendations, they are at the level of final approval. One of the coming

changes is if you have screened with ABR, you may rescreen with OAE, with the caveat of other than NICU babies. Babies with more than five days, rescreen is with ABR. Same thing with ototoxic drugs. Those are two of which I am aware. There's a whole new set of recommendations and sequence in there, including new recommendations on ZIKA. Terri shared that we do have ZIKA on the Newborn Hearing Screening form. If the new JCIH recommendations come out at the EHDI conference, Dr. Choo can present on those at a future Council meeting.

Some things that we do to help to reduce Lost to Followup that we'll continue to do. At three weeks a fax is sent to the primary care provider letting them know so that when the baby comes in for the checkup, that the baby did not pass the Newborn Hearing Screening. If the baby has an appointment scheduled, that's included on the fax and of course it reflects that the PCP stress the importance (did you go yet, are you going, etc.). The pediatricians can respond back. If they scheduled an appointment, they can let us know where it is scheduled. They will say my baby had an appointment; they fax results. Then we go back to the audiologist, and say okay report. Sometimes we get the response, 'not my patient'. We have lots of things in place to look through now. So if we get back the response 'not my patient', we ask do you know who you will followup with. Unfortunately, we have patients who say 'we do not know.' We have access to the Medicaid data, LINCSS, and WIC. All of that is not always as timely as we'd like it to be but we have started using that data. Tri will do a match and anytime we have a different pediatrician. Even though we've already sent a fax to the one that was noted on the NHS form, we send one to the one in WIC too, since that is probably the correct. We wait to six weeks to send a letter to the family. We know the families were told in the hospital that they needed to schedule a followup appointment. We hope they are going to do what they were told. The pediatrician is going to remind them. Then if we don't have something in the system that they were rescreened by six weeks, we will send the family a letter. In the letter it will tell them who the appointment was with initially with, contact them if you missed your appointment. The fax also has the Followup Coordinator's information on there. Any questions, you can always call. We also started a project, 'texting to families.' The problem with that is that we don't have a phone number on the NHS form. We get everything that Vital Records gets in their system. When babies are born, they don't fill out their phone number. What we do ask the screeners is that if the baby does not pass, please get the mom's phone number. We do have a place for that on the NHS form. Now we can't text a family until an audiologist tells us a baby is lost to followup. But now, we just started using the new forms at the end of December that have the phone number, so we should be getting the phone number initially. We had to wait to begin using the new forms until LEERS (Louisiana Electronic Events Registration System) was updated. They changed the NHS tab, so now it looks exactly like our pink form. Also at ten weeks, if there is nothing, we send a fax and a letter to the family. We use the WIC database for family addresses, since they often have a more current address. We use the Medicaid data and also the MCHVIE (Maternal Child Home Visiting program) data. Gina Easterly, the director of that program and member of the Council, will talk more about the MCHVIE program at a later Council meeting. But we use data from that program, to ensure every avenue to reach families is used.

Some things that contribute to high lost to followup: If a hospital has an extremely high refer rate, we take note. I think our current average hospital refer rate is about 5%. Usually it is wanted to be around 4%. Wendy Jumonville adds that it is usually around 2-4% for ABR. But if a hospital is like failing like 18% of the babies that are screened, then something is wrong

with the screening program. So then EHDI go in and try to help the hospital, What's wrong? Is your equipment too old? are you using the wrong probes? We send our audiologist to the hospital. We also go because sometimes it is recording, etc. so we go to followup. Sometimes its inaccurate information to families. There's a fine line between stressing the importance of followup and alarming a parent. The way information is provided can also contribute to lost to followup. If followup appointments are not scheduled prior to discharge, they are more likely to become lost to followup. A shortage of pediatric audiologist is rural areas and transportation issues. Timely followup reporting also contributes. Sometimes followup has been done, yet not reported. The more involved the medical home is, then the more successful the followup process will be.

The 1-3-6 goals to review, before one month age, every baby should be screened. Before 3 months of age diagnosis. By 6 months aided if hearing aids are appropriate, aided and in early intervention. The reason for the 6 month of age is that the research shows that the findings of Christie Yoshinaga-Itano how that babies that are aided and in early intervention before six months of age versus after six months, their receptive and expressive language levels are significantly higher, their language development advantage applies regardless of cognitive development to children with mild, mild to moderate, moderate, moderate to severe, severe, severe to profound (any loss) regardless to mode of communication. Regardless if its signed or spoken, there is always the language advantage. It all goes back to the age when intervention begins.

Based on our 2015 data, as you can see: 36% of the children who are diagnosed through the EHDI program have a unilateral hearing loss; 10% have a mild loss, with the remainder shown on the slide. So 65% of the children diagnosed through the EHDI program are hard of hearing. 28% of the kids diagnosed through the program are deaf and 5% have auditory neuropathy, auditory dyssynchrony.

So what happens when EHDI is notified that a child is identified that is deaf or hard of hearing? Once the followup services report is received from the audiologist (and we are working with audiologists on the timely submission of reporting – should be done within 48 hours), within 24 hours the EHDI program takes that form and makes referrals to the Louisiana School for the Deaf's Parent Pupil Education program for the outreach teachers who are teachers of the deaf to contact the family. They should be contacting the family within three days. They are also referred to the Guide By Your Side program for parent-to-parent support. All of the Parent Guides are parents of children who are deaf or hard of hearing. Immediately that's what a parent wants is to talk with another mom who has walked in their shoes. We give them a little bit more time so that not everyone is contacting then at the same time. EHDI also makes the referral to the Early Steps program. The reason we make the referral to the Parent Pupil Education program (PPEP) first is because the initial contact is with someone knowledgeable about children who are deaf or hard of hearing. If we go through Early Steps first and go through the intake process, that is how it was before, we found it would take up to 45 days to communicate with someone knowledgeable about hearing loss. Right now we have an Agreement. After the end of the grant period, we hope to have an official Memorandum of Understanding. This is a flyer about PPEP. Susannah Boudreaux is the program Coordinator adds that tucked into the folder, there are brochures and an update of recent activities of PPEP. They are teachers of the deaf, do home visits, and provide unbiased information and support. Then the Guide By Your Side program's brochure is there. Each Parent Guide is parent of a

child with hearing loss, they are all trained and provide unbiased support. Guide By Your Side is a program under Hands & Voices. Louisiana Hands & Voices is the state chapter under Hands & Voices national. They provide activities and trainings for families, either social or educational.

EHDI Reauthorization. Rana Ottallah, Lead ASTra Advocate for Louisiana Hands & Voices, presented on the new EHDI Reauthorization. One of the major changes in this bill is that everywhere that infant and newborn was used in the bill, they are adding young children or childhood and this is up to age three. Mentioned also is family members in education and training. It includes educational intervention, audiologic intervention, medical intervention and communication. So we are seeing the parents being part of education and training. Early intervention definition is expanded to include schools, community organizations, consumer agencies, family based agencies and medical home. The bill is specific and clear about the kind of information shared with parents when it comes to hearing technologies and communication modalities. The actual highlighted EHDI Reauthorization bill is attached hereto. Terri adds that this is federal, and that the federal grantees, the MCHB and the CDC were very aware of these changes and so they made their funding opportunities to match them. The family to family support, the Deaf mentor program, all of that will be completely be initiated by the end of our three year grant. Jay Isch asked if there was more information about the Deaf mentor program. Terri shared that EHDI has goals and activities in our MCHB grant. The goal at the end of three year period is to have created in Louisiana a Deaf mentor program. Our activities for year one, which ends March 31, included exploring other deaf mentor programs in other states and also collaborating with Hands & Voices national is presenting programs on established Deaf mentor programs. Jay asked if there was not a functioning deaf mentor program in Louisiana, and Susannah shared that Deaf mentors are available at functions and events through LSD, yet it is not a separate program in itself, but opportunities are available. Rana also shared that there is the Family Leadership Language Learning program (FL3) portion of the Hands & Voices website which houses a lot of this information. It is also linked on Louisiana Hands & Voices webpage as well www.lahandsandvoices.org.

Brochures. These are current EHDI brochures. The Can Your Baby Hear? Brochure is meant for awareness given prior to birth so that you know that after your child is born, your child will be screened in the hospital prior to discharge. We call this our awareness brochure. This other brochure is to be shared with families who child does not pass the NHS and needs further testing. We call this our refer brochure. We have funding to revise this brochure. These were prepared ten years ago. There are brochures out there from other states, and we can review what other states use. These are also available in Spanish. Dr. Kanotra queries if they are standard. Terri informs that these are not standard. The CDC and other organizations put them out and were used to prepare these. If we find a national one, we could put our name on it. When we put this together, we didn't find one we wanted to use. I think our Brochure Committee's first task should be to find brochures. We will have a LEND student and I will put them on the project. One of their first tasks will be to research to find other brochures. Marbely Barahona, Gina Easterly, Susannah Boudreaux, Dr. Kanotra, Jay Isch, Ariel Bumbala and Jay Isch volunteered to be on the Brochure Committee. The importance to be mindful of the purpose of the brochures will be key for the committee to keep in mind.

Update on Council vacancies. Currently vacancies exist for pediatrician and neonatologist. Hospital administration representative is done, just not yet appointed officially.

Next Advisory Council Meeting:

The next Advisory Council meeting will convene Friday, April 27, 2018 location TBA, preferably in LaPlace.

Adjournment:

A motion to adjourn the meeting was made by Dr. Choojitrom and seconded by Gina Easterly. By unanimous vote the meeting was adjourned.

